

# PACTALS

Pan-Asian Consortium for Treatment and Research in ALS

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## Meeting report of 5<sup>th</sup> PACTALS Meeting, Kyoto, Japan

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The 5<sup>th</sup> PACTALS meeting was jointly held with the “Brain Protein Aging and Dementia Control” project on 21 September 2017 at Grand Prince Hotel, Kyoto, Japan. The event was hosted by Professor Gen Sobue from Nagoya University. The theme of the meeting was “Promoting excellence in ALS registry and research”.

The meeting began at 2.30 pm with opening remarks from Gen Sobue (Japan) who thanked everyone for their participation and discussed an overview of therapeutic innovation in ALS over the years. This was followed by remarks from Matthew Kiernan (Australia), reiterating the strength in developing an Asia-Pacific collaborative network such as PACTALS.

The first session was the Young Researchers’ Progress Report which was chaired by Osamu Onodera from Niigata University, Japan. Presentations were given by Yohei Iguchi from Nagoya University (Title: Emerging roles of exosomes in TDP-43 proteinopathy) and Morio Ueyema from Osaka University (Title: “Repeat associated non-ATG translation and its regulation in C9orf72-associated amyotrophic lateral sclerosis/frontotemporal dementia model fly”).

The second session was moderated by Ryuji Kaji from Tokushima University, Japan. The first speaker was James Rooney from Trinity College, Dublin, Ireland who shared the experience from the European ALS Registry which has formed the foundation of ALS research in Europe. The ENCALS Registry has helped minimise bias in data acquisition and facilitated collaboration between countries. The second speaker was Hiroshi Mitsumoto from Columbia University, USA who shared the ALS Registry in USA. He discussed the different types of Registers in US which include mandatory reporting in certain States and a Federal-based voluntary reporting. Dr Mitsumoto also discussed hopes of a global “Dream Registry” which is multinational, multi-funded and multipurpose enabling activities including clinical trials, studies, biomarker development and epidemiology studies at a global setting.

The third session was the Japanese ALS Registry and Research which was moderated by Satoshi Kuwabara from Chiba University, Japan. The first speaker was Gen Sobue from Nagoya University, Japan who provided an overview of research from the Japanese ALS Consortium (JaCALS) through the JaCALS database. This included the identification of several

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genetic modifier genes, the Edaravone Clinical Trial and validation of the long-term outcome with Edaravone using the JaCALS natural history data. The talk was followed by “Hot Topics” on TDP-43 prions by Masato Hasegawa from Tokyo Metropolitan Institute of Medical Science, Japan and Osamu Onodera from Niigata University, Japan who discussed the molecular mechanisms in ALS.

The fourth session was on ALS Registry and Research Topics from PACTALS which was chaired by Nortina Shahrizaila (Malaysia). The first speaker was Paul Talman (Australia) who discussed the proposal for the PACTALS Registry. The Registry would be web-based data entry with an overarching Ethics approval that allows de-identified patient data from member countries to be hosted on one platform. Individual member countries choosing to include data on PACTALS Register will require local Ethics approval prior to including patient information into Registry. It was proposed that the PACTALS Registry be governed by the PACTALS Steering Committee comprising of representatives from the different contributing Member countries. The second speaker for the session was Yutaka Ogino from National Hakone Hospital, Japan who discussed the preliminary data from the study on the Standards of ALS/MND care from PACTALS countries. This was a questionnaire-based survey that received 41 responses from 9 countries in the region. The initial findings found similar standards to that in the West although there were circumstances where social and cultural diversities had an impact on the decision-making process such as the use of tracheostomy positive pressure ventilation. The third speaker was Dongsheng Fan from Peking University Third Hospital, China who presented measures on standardizing research methodology in PACTALS. He shared the development of the Chinese ALS network ([www.chalsr.net](http://www.chalsr.net)) which has 11 key independent researchers, 20 Chinese ALS organisations and 60 hospitals. Recommendations for the optimum core dataset based on a hierarchy system were presented.

The closing remarks were made by Gen Sobue thanking everyone for their contribution and highlighting the need for the Group to work towards identifying the core minimum dataset that can align the various Patient Registers in the region.

The next PACTALS meeting will be held in South Korea in 2018 organised by Professor Seung Hyun Kim from Hanyang University Medical Centre, Seoul, South Korea. There will also be a Satellite meeting during the International ALS Symposium in Boston. Further details on both meetings will be disseminated at a later stage.